

**University of Groningen**

## **Physical activity and physical fitness in juvenile idiopathic arthritis**

Lelieveld, Otto

**IMPORTANT NOTE: You are advised to consult the publisher's version (publisher's PDF) if you wish to cite from it. Please check the document version below.**

*Document Version*

Publisher's PDF, also known as Version of record

*Publication date:*

2010

[Link to publication in University of Groningen/UMCG research database](#)

*Citation for published version (APA):*

Lelieveld, O. (2010). *Physical activity and physical fitness in juvenile idiopathic arthritis*. s.n.

### **Copyright**

Other than for strictly personal use, it is not permitted to download or to forward/distribute the text or part of it without the consent of the author(s) and/or copyright holder(s), unless the work is under an open content license (like Creative Commons).

The publication may also be distributed here under the terms of Article 25fa of the Dutch Copyright Act, indicated by the "Taverne" license. More information can be found on the University of Groningen website: <https://www.rug.nl/library/open-access/self-archiving-pure/taverne-amendment>.

### **Take-down policy**

If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.

*Downloaded from the University of Groningen/UMCG research database (Pure): <http://www.rug.nl/research/portal>. For technical reasons the number of authors shown on this cover page is limited to 10 maximum.*

## *Chapter 6*

### **Illness representations and the relationship with functional status in adolescents with juvenile idiopathic arthritis**

Otto T.H.M. Lelieveld<sup>1</sup>, Wineke Armbrust<sup>2</sup>, Miek A. van Leeuwen<sup>3</sup>, Jan H.B. Geertzen<sup>1,4</sup>, Pieter J.J. Sauer<sup>2</sup>, Ellen van Weert<sup>1,4</sup>.

<sup>1</sup>Center for Rehabilitation, <sup>2</sup>Beatrix Children's Hospital, <sup>3</sup>Department of Rheumatology and Clinical Immunology, <sup>4</sup>SHARE, Graduate School for Health Research, University Medical Center Groningen (UMCG), University of Groningen, Groningen, the Netherlands.

Submitted

## **Abstract**

### *Objective*

Illness representations are opinions that patients have about their illness which can affect coping and outcome. The objective of this study was to explore illness representations of adolescents with juvenile idiopathic arthritis (JIA) and to examine associations between these representations and functional status.

### *Methods*

Illness representations (8 dimensions) were assessed with the Illness Perception Questionnaire Revised (IPQ-R). Functional status was determined by aerobic capacity, physical activity and functional ability. Functional ability was assessed with the Childhood Health Assessment Questionnaire, aerobic capacity using a Symptom Limited Bicycle Ergometry test and physical activity with a 3-day activity diary. Disease activity was classified using Wallace criteria.

### *Results*

Thirty-five adolescents were included (mean age  $\pm$  SD  $17.1 \pm 0.7$  years). Adolescents with JIA perceive JIA as a chronic disease causing no emotional distress and as having little impact on their life. Stiff joints, pain and fatigue were most commonly experienced and attributed by patients with and without active disease. Although they perceive JIA as a comprehensible disease they have an indifferent view towards the cyclical and unpredictable disease course. Significant associations were found between functional status and the dimensions of IPQ-R “identity”, “timeline cyclical”, “consequences”, “emotional representation” and “illness coherence”.

### *Conclusion*

Adolescent’s explicit views towards JIA are related to aspects of functional status. In order to improve functional status clinicians should also address issues like health education and adolescent’s individual views towards JIA.

## Introduction

Juvenile idiopathic arthritis (JIA) is the most common chronic rheumatic disease in childhood causing short- and long term disability<sup>1</sup>. Long term follow up studies over the last 12 years show that between 37 and 53% of JIA patients had active disease and between 2.5 and 37 % had severe functional impairments<sup>2-7</sup>. Additionally, periods of active disease alternate with periods of remission and many take their disease into adulthood<sup>8, 9</sup>. JIA is a life-changing experience demanding adaptation to other lifestyles, circumstances and opportunities<sup>10</sup>. It has been reported that children and adolescents with JIA, with and without active disease, have low physical fitness levels and are less physically active compared to healthy age mates<sup>11-15</sup>.

Today it is recognized that an “open approach” towards children about their disease is favored upon a “protective approach”<sup>16</sup>. In an open approach one informs a child fully about the nature and consequences of the disease and its treatment. Children are seen as actors participating in disease management processes<sup>17</sup>. It allows children to pertain control over their disease by means of their own behavior. A “protective approach” whereby children are shielded against the nature and consequences of their disease may result in children fantasizing and not taking responsibility. It was previously shown that early knowledge of diagnosis was related to good psychosocial adjustment among long term survivors of childhood malignancies<sup>18</sup>.

The common sense model (CSM) conceptualizes that patient’s coping and outcome with disease is facilitated by organized cognitive representations of the disease called illness representations<sup>19-21</sup>. Illness representations are opinions that patients have about their illness which are based on the present and past experienced symptoms combined with pre existing knowledge and moderated by the patient’s personal, social and cultural context. In this dynamic cognitive process five attributes of illness representations are formed by the patient: identity, timeline, cause, controllability and consequences. It is important for clinicians to understand and recognize how illness representations guide patient’s preferences for treatment and coping strategies and affect adaptation and functioning<sup>19</sup>. Several researchers have studied the influence of illness representations on coping and outcome in a number of acute and chronic diseases like chronic fatigue syndrome, rheumatoid arthritis, chronic obstructive pulmonary disease, psoriasis and irritable bowel syndrome<sup>22-27</sup>. There is some evidence that self-reported physical and mental health of patients consulting the general practitioner is predicted by patient’s perception of a new or recurrent health problem<sup>28</sup>. Evidence is also

accumulating that illness representations are associated with coping and outcome in chronic disease<sup>29, 30</sup>.

Until now, illness representations of children and adolescents with JIA and their influence on functioning are unknown. It is therefore the aim of this study to explore illness representations of adolescents with JIA and to examine associations between these representations and functional status.

## **Methods**

### *Patients*

All patients attending the adolescent JIA clinic of the University Medical Center Groningen were selected for this study. The adolescent JIA clinic, started in 2003 to improve transitional care, is a combined outpatient clinic of the Beatrix Children's Hospital and the adult rheumatology clinic of the University Medical Center Groningen. Patients referred are post pubertal and are at least 16 years of age. Eligible patients were diagnosed by a pediatric rheumatologist using the International League of Associations for Rheumatology (ILAR) criteria<sup>31</sup>. Data concerning exercise capacity, physical activity and illness representation were collected. Adolescents were fully informed about the protocol and written informed consent was obtained from them. Age, gender and JIA subtype were registered. Disease duration was defined as the period of time between disease onset and time of assessment. Weight and height were determined using an electronic scale and a stadiometer. Body mass index (BMI) was calculated as body mass/height<sup>2</sup>. The study was approved by the local ethics committee.

### *Disease activity*

Disease activity was assessed by an adult and a pediatric rheumatologist using core set criteria<sup>32, 33</sup>. Disease activity was classified using Wallace criteria as active disease, inactive disease, clinical remission on medication and clinical remission off medication. Active disease was defined as active arthritis being present in one or more joints, inactive disease as no signs of disease with medication and clinical remission on medication as six continuous months without active disease on medication. Twelve months off medication and no signs of active disease was defined as clinical remission off medication.

### *Illness representations*

Illness representations were assessed with the Illness Perception Questionnaire Revised (IPQ-R)<sup>34,35</sup>. The IPQ-R includes a quantitative assessment of the attributes of illness representations following eight dimensions. All these dimensions, excluding “identity”, are rated by answering questions by the adolescent on a 5-point Likert scale (strongly disagree, disagree, neither agree nor disagree, agree and strongly agree). The dimension “identity”, reflecting the adolescent’s ideas about the number of somatic symptoms attributed to the JIA, consists of 14 commonly experienced symptoms (pain, sore throat, nausea, breathlessness, weight loss, fatigue, stiff joints, sore eyes, wheeziness, headaches, upset stomach, sleep difficulties, dizziness and loss of strength). The adolescent is asked whether or not a symptom is experienced and if they attribute the symptom to JIA. The number of symptoms attributed to the JIA is counted. Higher scores mean a stronger illness identity. The dimension “timeline acute/chronic” (explored by 6 questions) reflects the expected duration of the JIA while “timeline cyclical” (explored by 4 questions) reflects an unpredictable and cyclical disease course. The dimension “consequences” (6 questions) refers to the ideas about the seriousness of the JIA. High scores represent strongly held beliefs about the chronicity of the JIA, its unpredictable and cyclical nature and the serious consequences of the JIA respectively. The dimension “personal control” (6 questions) refers to the amount of self-efficacy of the adolescent to control the disease whereas “treatment control” (5 questions) reflects adolescents belief in JIA treatment and advice. “Illness coherence” (5 questions) reflects how much an adolescent with JIA understands his or her disease. High scores represent positive and strong beliefs about the controllability of the JIA respectively a personal understanding of the disease. The dimension “emotional representation”, explored by 6 questions, reflects adolescent’s feelings and emotions like depression, upset, anger, worry, anxiousness and fear and high scores reflect strong emotional feelings.

### *Functional status: physical activity, aerobic capacity and functional ability*

**Physical Activity** Physical activity (PA) was assessed with a 3-day activity diary and the data have been reported in a separate publication<sup>13</sup>. Patients were asked to record their level of activity for three days in one week, of which one of these days had to be in a weekend, on a pre-printed form. The dominant activity of every quarter of an hour had to be scored using a number from 1 up to 9 representing 1 = resting prone; 2 = seated activities; 3 = standing activities; 4 = walking indoors (less than 4 km/hour), light home activities; 5 = walking

outdoors (4-6 km/hour), housekeeping; 6 = recreational sport and leisure time activities with low intensity; 7 = recreational sport and leisure time activities with moderate intensity; 8 = recreational sport and leisure time activities with high intensity; 9 = competition sport. A physical activity ratio (PAR), which is the ratio of the energy expended by an individual in a particular category as multiples of basal metabolic rate (BMR), was allotted to each of the different nine categories following the modification of Bratteby et al<sup>36</sup>. Total energy expenditure (TEE) was calculated by summing up all 15 minute periods of each category, dividing them by 96 and multiplying them by the PAR value of each category and the predicted basal metabolic rate (BMRp) after which all categories were added up. The prediction formula according to Schofield was used. BMRp for boys =  $0.074 \times \text{bodyweight in kilograms} + 2.754 \text{ MJ/day}$ , and BMRp for girls =  $0.056 \times \text{bodyweight in kilograms} + 2.898 \text{ MJ/day}$ . PA is expressed as activity-related energy expenditure (AEE) and is calculated as 0.9 times the TEE minus the BMR, assuming a diet induced thermo genesis (DIT) of 10%<sup>37</sup>. To rule out gender differences between boys and girls in PA, AEE is expressed as percentage of predicted. Predicted values for boys and girls were obtained from matched controls<sup>13</sup>.

*Aerobic capacity* Aerobic capacity was measured with a Symptom Limited Bicycle Ergometry test (SLBE) on an electronically braked cycle ergometer (Jaeger physis hc, Viasys, the Netherlands) as described before<sup>12</sup>. The seat-height was adjusted to patient's comfort. Rest was taken till all measured variables were stable. Cycling started at a workload of 0 Watt and the workload was increased with 20 Watt every minute until the patient stopped due to volitional exhaustion, despite strong verbal encouragement from the experimenters. Patients breathed through a mouth piece which was connected to a calibrated metabolic cart (Oxycon pro, Jaeger, Viasys, The Netherlands). Expired gas was passed through a flow meter, an oxygen (O<sub>2</sub>) analyzer, and a carbon dioxide (CO<sub>2</sub>) analyzer. The flow meter and gas analyzer were connected to a computer, which calculated breath-by-breath minute ventilation (VE), oxygen consumption (VO<sub>2</sub>), carbon dioxide production (VCO<sub>2</sub>) and respiratory exchange ratio (RER) from conventional equations. VO<sub>2</sub>, VCO<sub>2</sub> and RER were recorded at 30 seconds intervals. Heart rate (HR) was measured continuously during the maximal exercise test. VO<sub>2</sub> at maximal effort was recorded as VO<sub>2peak</sub> and expressed in milliliters per kilogram per minute. To correct for age and gender VO<sub>2peak</sub> is expressed as percentage of predicted from age and sex- matched historical Dutch controls<sup>38</sup>.

*Functional ability* Functional ability was assessed with the validated Dutch translation of the Childhood Health Assessment Questionnaire (CHAQ)<sup>39, 40</sup>, including questions for the

following domains: dressing/grooming, arising, eating, walking, hygiene, reach, grip and activities (range 0 to 3; 0 = able to do with no difficulty; 1 = able to do with some difficulty; 2 = able to do with much difficulty; 3 = unable to do). When assistance or aids were required for a domain the score for that domain was raised to a minimum of 2. Time period for the self assessment was one week. The mean of the eight scores determined the CHAQ score (range 0 to 3), higher scores indicate more disability.

### *Statistical analysis*

The Statistical Package for Social Sciences (SPSS Version 14) was used for statistical analysis. Descriptive statistics (mean, standard deviation (SD), range and percentage) were used for patients' characteristics. Cronbach's alpha was used to measure internal reliability of the CHAQ and of the dimensions of the IPQ-R excluding "identity". Items with a Cronbach's alpha of 0.6 or more were considered to have acceptable internal reliability. Pearson correlations were used to explore associations between illness representations and aerobic capacity, physical activity and functional ability. The Bonferroni Hochberg correction was used to calculate and control the  $\alpha$  level for significance<sup>41</sup>. The *P*-levels are arranged in order from the smallest to the largest. For significance *p* must be smaller than the rank order divided by the total number of the tests and multiplied by 0.05.

## **Results**

### *Patients*

Thirty-five adolescents participated in the study, 14 boys and 21 girls, with a mean  $\pm$  SD age of  $17.1 \pm 0.7$  years. One patient was not included because of Down syndrome. Three patients were not willing to participate. The population consisted of one adolescent with systemic JIA, 9 adolescents with oligo-articular JIA, 3 adolescents with extended oligo-articular JIA, 13 adolescents with poly-articular rheumatoid factor (RF)-negative JIA, 4 adolescents with poly-articular RF-positive JIA, 2 adolescents with psoriatic arthritis and 3 adolescents with enthesitis related JIA. Disease duration was on average  $8.4 \pm 5.0$  years indicating a childhood onset of disease in most patients. There were no patients with severe physical disability requiring joint replacement surgery. Patient characteristics are presented in Table 1.



**Table 1. Characteristics of the patients with juvenile idiopathic arthritis (JIA)\***

Characteristic	(n = 35)
Age, years	17.1 ± 0.7 (16.0-18.2)
Height, cm	173.4 ± 8.3 (157-190)
Weight, kg	62.0 ± 12.9 (42.0-91.0)
Body mass index, kg·m <sup>-2</sup>	20.8 ± 3.3 (14.5-29.4)
Disease duration since onset, years	8.4 ± 5.0 (0.5-16.7)
AEE (MJ x.day <sup>-1</sup> ) (n = 30) <sup>13</sup>	3.99 ± 2.20 (0.72-9.61)
AEE, percentage of predicted	66 ± 35 (10-162)
VO <sub>2 peak</sub> , (ml x.kg <sup>-1</sup> .x minute <sup>-1</sup> )	35.87 ± 7.48 (22.50-53.80)
VO <sub>2 peak</sub> , percentage of predicted	82 ± 13 (57-106)
CHAQ score (range 0-3)	0.44 ± 0.48 (0.0-1.75)

\* Values are the mean ± SD (range)

AEE: activity related energy expenditure; MJ = megajoule; VO<sub>2 peak</sub> : peak oxygen uptake,  
CHAQ: Childhood Health Assessment Questionnaire

### *Disease activity*

Nine adolescents had active disease, 11 had inactive disease with medication, 9 adolescents were in clinical remission on medication and 6 adolescents were in clinical remission off medication.

### *Illness representations (table 2)*

Cronbach's alpha for "treatment control" and for "personal control" were 0.09 and 0.52 respectively. Internal consistency of these dimensions were therefore considered to be too low and they were excluded from further analysis.

**Identity** Out of 35 adolescents 3 (9%) adolescents experienced no symptoms; 6 (17%) adolescents experienced symptoms not attributed to the JIA; 26 (74%) adolescents experienced symptoms which they attributed to the JIA. The average number of symptoms attributed to the JIA was 2.5 and stiff joints (63%), pain (57%) and fatigue (49%) were most commonly experienced and attributed to the disease. Of the 9 adolescents with active disease 6 (66%) experienced and attributed stiff joints, 5 (55%) pain and 4 adolescents (44%) experienced and attributed fatigue to the JIA. Of the 6 adolescents in remission off medication 4 (66%) experienced and attributed stiff joints, 3 (50%) pain and 2 adolescents (33%) experienced and attributed fatigue to the JIA. Headache was an often experienced symptom (29%) but was not by any adolescent attributed to JIA.

**Table 2. Illness representations in adolescents with JIA\***

<b>Illness representation (Range questionnaire)</b>	<b>Mean <math>\pm</math> SD</b>	<b>Range</b>	<b>Cronbach's alpha</b>
Identity/number of attributed symptoms (0-14)	2.5 $\pm$ 2.0	0 - 7	n/a
Timeline acute/chronic (6-30)	21.9 $\pm$ 3.9	11 - 29	0.86
Timeline cyclical (4-20)	13.1 $\pm$ 3.2	5 - 19	0.76
Consequences (6-30)	14.2 $\pm$ 3.3	6 - 21	0.67
Illness coherence (5-25)	20.1 $\pm$ 2.7	13 - 25	0.82
Emotional representation (6-30)	12.9 $\pm$ 3.4	6 - 22	0.82

\* SD: standard deviation, n/a = not applicable

Timeline acute/chronic Mean score indicate that adolescents with JIA perceive JIA as a chronic disease.

Timeline cyclical Mean score indicate an indifferent perception towards a cyclical unpredictable disease course.

Consequences Mean score indicate that adolescents with JIA perceive JIA as a disease with no consequences and impact on their lives.

Illness coherence Mean score indicate that adolescents with JIA perceive their disease as something they fully comprehend.

Emotional representation Mean score indicate that adolescents with JIA perceive their disease as something that doesn't make them feel depressed, upset, angry, worried, anxious or feel afraid.

### *Functional status*

Thirty out of 35 adolescents (86%) returned their activity diaries and were included in the analysis of physical activity. Cronbach's alpha for the CHAQ was 0.88 indicating good internal consistency. The mean, standard deviation, range and if applicable percentage of predicted AEE,  $VO_{2\text{ peak}}$  and CHAQ are given in Table 1.

### *Correlations*

Functional ability was significantly and positively associated with "timeline cyclical" ( $r = 0.44$ ), "consequences" ( $r = 0.57$ ), "emotional representation" ( $r = 0.41$ ) and "identity" ( $r = 0.47$ ) indicating that patients who view their JIA as more cyclical, having more consequences, having more emotional distress and attributing more symptoms to their JIA experience lower levels of functional ability. Physical activity was significantly and positively associated with

“illness coherence” ( $r = 0.47$ ) indicating that adolescents who better comprehend their JIA have higher levels of physical activity. We found no significant associations between  $VO_{2\text{peak}}$  and illness representations (Table 3).

**Table 3. Pearson correlation coefficient between illness representation and  $VO_{2\text{peak}}$ , AEE and CHAQ\***

	<b>Timeline acute/chronic</b>	<b>Timeline cyclical</b>	<b>Consequences</b>	<b>Illness coherence</b>	<b>Emotional representation</b>	<b>Identity</b>
$VO_{2\text{peak}}$	- 0.36	- 0.04	- 0.06	0.14	0.01	0.18
AEE	- 0.31	- 0.08	- 0.14	0.47†	- 0.25	- 0.39
CHAQ	0.13	0.44†	0.57†	- 0.11	0.41†	0.47†

\*  $VO_{2\text{peak}}$  : peak oxygen uptake in ml/kg/min, AEE: Activity related Energy Expenditure (megajoule x day<sup>-1</sup>), CHAQ: Childhood Health Assessment Questionnaire (range 0-3)

†  $p < i/18 * 0.05$  (i is order of p with 1 for lowest p-value and 18 for highest p-value)

## Discussion

Adolescents with JIA participating in this study perceive JIA as a chronic disease causing no emotional distress and as having little impact on their life. Although they perceive JIA as a comprehensible disease they have an indifferent view towards the cyclical and unpredictable disease course. Only a small proportion of the study group of adolescents with JIA had active disease. The level of self-reported disability was low but physical activity and aerobic capacity were impaired compared to healthy peers<sup>12, 13</sup>. Stiff joints, pain and fatigue were most commonly experienced and attributed also by those patients without active disease. Furthermore the present study revealed significant associations between dimensions of illness representations and functional status.

This is the first study to explore illness representations among adolescents with JIA and to assess associations between them and functional status. It is important for clinicians to understand and appreciate patient's illness representations since they might influence coping and eventual outcome. Understanding illness representations and how they affect coping and outcome is also useful for the development of new interventions. The present study showed for example high levels of symptoms like stiff joints, pain and fatigue also in those patients with inactive disease. Schanberg et al analysed patterns of self reported disease symptoms in children and adolescents with JIA, aged 8 to 17 years using a prospective daily diary and found that they reported pain, stiffness and fatigue on a majority of days despite treatment<sup>42</sup>.

The same study found that daily fluctuations in both stress and mood were predictive of increased pain, stiffness and fatigue<sup>42</sup>. They also found that increased daily stress, mood and reported symptoms were significantly related to decreased participation in social activities<sup>42</sup>. Sallfers et al described a model for predicting well-being in children and adolescents with JIA, aged 10 to 18 years, and found that pain was a robust predictor but not fatigue<sup>43</sup>. They also found that increased pain was related with a significant reduction in attending physical education classes at school<sup>43</sup>. Only a minority of the included patients' in this study had active disease<sup>43</sup>. A systematic review assessing the relationship between fatigue and quality of life in children with chronic health problems found that children often reported fatigue and that it decreased quality of life<sup>44</sup>. The present study showed also a significant and positive association between "identity" and functional ability. These findings indicate that the perseverance of reported symptoms in those with inactive disease might have a direct and negative impact on functional ability. This may imply that in order to improve functional ability, interventions should also address issues like pain and energy management. This finding is in line with the results of a meta-analytic review of the common sense model from Hagger et al, examining 23 illnesses and conditions, which showed that strong "identity" perceptions are negatively associated with physical functioning<sup>45</sup>.

Is it possible that the adolescents in this study underrate this chronic and often serious condition? The adolescents with JIA in this study perceive their disease as having little impact on their lives and causing no emotional distress. Besides this the adolescents perceive their JIA as a chronic disease but they are indifferent towards its cyclical and unpredictable nature. Adolescents with JIA are less fit and less physically active than their healthy peers<sup>12, 13</sup>. We have experienced that once adolescents with JIA have to engage in strenuous periods of work practice during their vocational training, many of them face difficulties in fulfilling the demands of the work. Foster and Packham found a high rate of unemployment despite excellent educational attainment in two large cohorts of adults with JIA<sup>2, 46</sup>. These are signs that it is indeed possible that these adolescents do underrate their disease. We therefore advocate that interventions during transitional care should better prepare these youngsters for the future and strengthen abilities in the physical as well as in the psycho-social domain. An important finding in our study was the positive association between "illness coherence" and physical activity indicating that those adolescents who have a more coherent understanding of their disease are more physically active. This may indicate that those adolescents who grasp their JIA may be able to develop a more active life style. It supports the notion of adequate

disease-related health education and thus an open approach in which patients are adequately informed about JIA and the consequences. Another argument for adequate disease-related health education is our finding that four out of the six analysed dimensions of illness representations were significantly associated with functional ability. It shows their reciprocity but how they influence each other remains unclear. However, shaping health beliefs might be a possible mode of improving functional ability. These findings are again in line with the meta-analysis by Hagger et al which reported that “consequences” and “timeline” are significantly associated with physical functioning<sup>45</sup>.

This study has a number of limitations. We have explored the illness representations of a relatively small group of post-pubertal late adolescence patients with JIA. We can not generalise the results to the whole JIA population. We think it may be appropriate to measure illness representations longitudinally to gain a better insight into the whole group and over time.

We conclude that adolescent’s explicit views towards JIA are related to functional ability and PA but not to aerobic capacity. Although the induction of disease control through medication should have high priority in disease management, clinicians should also address issues like health education and adolescent’s individual views towards JIA to improve aspects of functional status.

## References

1. Ravelli A, Martini A. Juvenile idiopathic arthritis. *Lancet* 2007; **369**:767-778.
2. Foster HE, Marshall N, Myers A, Dunkley P, Griffiths ID. Outcome in adults with juvenile idiopathic arthritis: a quality of life study. *Arthritis Rheum* 2003; **48**:767-775.
3. Minden K, Niewerth M, Listing J, Biedermann T, Bollow M, Schontube M et al. Long-term outcome in patients with juvenile idiopathic arthritis. *Arthritis Rheum* 2002; **46**:2392-2401.
4. Oen K, Malleson PN, Cabral DA, Rosenberg AM, Petty RE, Cheang M. Disease course and outcome of juvenile rheumatoid arthritis in a multicenter cohort. *J Rheumatol* 2002; **29**:1989-1999.
5. Packham JC, Hall MA. Long-term follow-up of 246 adults with juvenile idiopathic arthritis: functional outcome. *Rheumatology* 2002; **41**:1428-1435.
6. Ravelli A. Toward an understanding of the long-term outcome of juvenile idiopathic arthritis. *Clin Exp Rheumatol* 2004; **22**:271-275.
7. Zak M, Pedersen FK. Juvenile chronic arthritis into adulthood: a long-term follow-up study. *Rheumatology* 2000; **39**:198-204.
8. Wallace CA, Huang B, Bandeira M, Ravelli A, Giannini EH. Patterns of clinical remission in select categories of juvenile idiopathic arthritis. *Arthritis Rheum* 2005; **52**:3554-3562.
9. Wallace CA. Current management of juvenile idiopathic arthritis. *Best Pract Res Clin Rheumatol* 2006; **20**:279-300.
10. Guell C. Painful childhood: children living with juvenile arthritis. *Qual Health Res* 2007; **17**:884-892.
11. Henderson CJ, Lovell DJ, Specker BL, Campaigne BN. Physical activity in children with juvenile rheumatoid arthritis: quantification and evaluation. *Arthritis Care Res* 1995; **8**:114-119.

12. Lelieveld OT, van Brussel M, Takken T, van Weert E, van Leeuwen MA, Armbrust W. Aerobic and anaerobic exercise capacity in adolescents with juvenile idiopathic arthritis. *Arthritis Rheum* 2007; **57**:898-904.
13. Lelieveld OT, Armbrust W, van Leeuwen MA, Duppen N, Geertzen JH, Sauer PJ et al. Physical activity in adolescents with juvenile idiopathic arthritis. *Arthritis Rheum* 2008; **59**:1379-1384.
14. Takken T, Hemel A, van der Net J, Helders PJ. Aerobic fitness in children with juvenile idiopathic arthritis: a systematic review. *J Rheumatol* 2002; **29**:2643-2647.
15. van Brussel M, Lelieveld OT, van der Net J, Engelbert RH, Helders PJ, Takken T. Aerobic and anaerobic exercise capacity in children with juvenile idiopathic arthritis. *Arthritis Rheum* 2007; **57**:891-897.
16. Eiser C. Explaining illness to children. *Communication & cognition* 1987; **20**:277-290.
17. Prout A. *The future of childhood*. London: RoutledgeFalmer; 2005.
18. Slavin LA, O'Malley JE, Koocher GP, Foster DJ. Communication of the cancer diagnosis to pediatric patients: impact on long-term adjustment. *Am J Psychiatry* 1982; **139**:179-183.
19. Hale ED. The common-sense model of self-regulation of health and illness: how can we use it to understand and respond to our patients' needs? *Rheumatology* 2007; **46**:904-906.
20. Leventhal H. Illness cognition: Using common sense to understand treatment adherence and affect cognition interactions. *Cognitive Therapy Res* 1992; **16**:143-163.
21. Leventhal H, Brisette I, Leventhal EA. The common-sense model of self-regulation of health and illness. In: Cameron LD, Levanthal H, editors. *The self-regulation of health and illness behaviour*. New York: Routledge; 2003. 42-65.
22. Gray SE, Rutter DR. Illness representations in young people with Chronic Fatigue Syndrome. *Psychology & health* 2007; **22**:159-174.
23. Groarke A. The impact of illness representations and disease activity on adjustment in women with rheumatoid arthritis: A longitudinal study. *Psychology & health* 2005; **20**:597-613.
24. Morris R. Illness perceptions and levels of disability in patients with chronic fatigue syndrome and rheumatoid arthritis. *J Psychosom Res* 2003; **55**:305-308.
25. Murphy H. Depression, illness perception and coping in rheumatoid arthritis. *J Psychosom Res* 1999; **46**:155-164.
26. Rutter CL, Rutter DR. Longitudinal analysis of the Illness Representation Model in patients with Irritable Bowel Syndrome (IBS). *J Health Psychology* 2007; **12**:141-148.
27. Scharloo M. Illness perceptions, coping and functioning in patients with rheumatoid arthritis, chronic obstructive pulmonary disease and psoriasis. *J Psychosom Res* 1998; **44**:573-585.
28. Frostholt L, Oernboel E, Christensen KS, Toft T, Olesen F, Weinman J et al. Do illness perceptions predict health outcomes in primary care patients? A 2-year follow-up study. *J Psychosom Res* 2007; **62**:129-138.
29. Hagger MS, Orbell S. A meta-analytic review of the common-sense model of illness representations. *Psychology & health* 2003; **18**:141-184.
30. Petrie KJ, Jago LA, Devcich DA. The role of illness perceptions in patients with medical conditions. *Curr Opin Psych* 2007; **20**:163-167.
31. Hofer M, Southwood TR. Classification of childhood arthritis. *Best Pract Res Clin Rheumatol* 2002; **16**:379-396.
32. Ravelli A, Martini A. Remission in juvenile idiopathic arthritis. *Clin Exp Rheumatol* 2006; **24**:S105-S110.
33. Wallace CA, Ruperto N, Giannini E. Preliminary criteria for clinical remission for select categories of juvenile idiopathic arthritis. *J Rheumatol* 2004; **31**:2290-2294.
34. Morris R, Weinman J, Petrie KJ, Horne R, Cameron LD, Buick D. The revised illness perception questionnaire (IPQ-R). *Psychology & health* 2002; **17**:1-16.
35. Weinman J. The Illness Perception Questionnaire: A new method for assessing the cognitive representation of illness. *Psychology & health* 1996; **11**:431-445.
36. Bratteby LE, Sandhagen B, Fan H, Samuelson G. A 7-day activity diary for assessment of daily energy expenditure validated by the doubly labelled water method in adolescents. *Eur J Clin Nutr* 1997; **51**:585-591.
37. Hoos MB, Gerver WJ, Kester AD, Westerterp KR. Physical activity levels in children and adolescents. *Int J Obes Relat Metab Disord* 2003; **27**:605-609.
38. Binkhorst RA, van 't Hof MA, Saris WHM. Maximale inspanning door kinderen; Referentiewaarden voor 6 - 18 jarige meisjes en jongens (Maximal exercise in children; reference values girls and boys, 6 to 18 year of age). Den-Haag: Nederlandse Hartstichting; 1992.

39. Singh G, Athreya BH, Fries JF, Goldsmith DP. Measurement of health status in children with juvenile rheumatoid arthritis. *Arthritis Rheum* 1994; **37**:1761-1769.
40. Wulffraat N, van der Net JJ, Ruperto N, Kamphuis S, Prakken BJ, Ten Cate R et al. The Dutch version of the Childhood Health Assessment Questionnaire (CHAQ) and the Child Health Questionnaire (CHQ). *Clin Exp Rheumatol* 2001; **19**:S111-S115.
41. Norman GR, Streiner DL. *Biostatistics, The bare essentials*. second edition ed. Hamilton, Ontario: Harcourt Publishers Limited; 2002.
42. Schanberg LE, Gil KM, Anthony KK, Yow E, Rochon J. Pain, stiffness, and fatigue in juvenile polyarticular arthritis: contemporaneous stressful events and mood as predictors. *Arthritis Rheum* 2005; **52**:1196-1204.
43. Sallfors C, Hallberg LR, Fasth A. Well-being in children with juvenile chronic arthritis. *Clin Exp Rheumatol* 2004; **22**:125-130.
44. Eddy L, Cruz M. The relationship between fatigue and quality of life in children with chronic health problems: a systematic review. *J Spec Pediatr Nurs* 2007; **12**:105-114.
45. Hagger MS, Orbell S. A meta-analytic review of the common-sense model of illness representations. *Psychology & health* 2003; **18**:141-184.
46. Packham JC, Hall MA. Long-term follow-up of 246 adults with juvenile idiopathic arthritis: education and employment. *Rheumatology* 2002; **41**:1436-1439.